Food and nutrition insecurity among adults with sickle cell disease: a scoping review

Insegurança alimentar e nutricional entre adultos com doença falciforme: uma revisão de escopo

Inseguridad alimentaria y nutricional entre adultos con enfermedad de células falciformes: una revisión exploratória

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RESUMO

Objetivo: Esta revisão teve como objetivo mapear as causas e as manifestações da insegurança alimentar e nutricional em adultos com doença falciforme. Foram incluídos estudos que envolviam pessoas entre 19 até 64 anos com doença falciforme e insegurança alimentar e nutricional, sem restrição de idioma no período de busca a partir do ano 2000. A revisão de escopo seguiu as recomendações propostas pelo manual do JBI. As fontes de buscas foram: *COCHRANE LIBRARY, EMBASE, LILACS*, SCIELO, *MEDLINE, SCOPUS, ScienceDirect*. Dentre os 2556 estudos mapeados somente 12 estudos foram incluídos. Observou-se que a insegurança alimentar foi mensurada por meio de indicadores antropométricos, consumo alimentar e o clínico biológico. Evidenciando uma lacuna de pesquisas para avaliação dos fatores sociodemográficos e outros relacionados à pobreza que determinam os padrões de acesso e disponibilidade de alimentos entre populações minoritárias que são afetadas pela doença falciforme.

Descritores: Insegurança Alimentar; Anemia Falciforme; Adulto.

ABSTRACT

Objective: This review aimed to map the causes and manifestations of food and nutritional insecurity in adults with sickle cell disease. Studies involving people aged 19 to 64 years with sickle cell disease and food and nutritional insecurity were included, with no language restriction in the search period from the year 2000 onwards. The scoping review followed the recommendations proposed by the JBI manual. The search sources were: *COCHRANE LIBRARY, EMBASE, LILACS*, SCIELO, *MEDLINE, SCOPUS, ScienceDirect*. Among the 2556 studies mapped, only 12 studies were included. It was observed that food insecurity was measured through anthropometric indicators, food consumption and clinical biological indicators. This highlights a research gap for evaluating sociodemographic and other poverty-related factors that determine patterns of access and availability of food among minority populations that are affected by sickle cell disease.

Descriptors: Food Insecurity; Sickle Cell Anemia; Adult.

RESUMEN

Objetivo: Esta revisión tuvo como objetivo mapear las causas y manifestaciones de la inseguridad alimentaria y nutricional (IAN) en adultos con enfermedad de células falciformes (ECF). Se incluyeron estudios con personas de 19 a 64 años con ECF e IAN, publicados desde 2000, sin restricción de idioma. La revisión siguió las directrices del Instituto Joanna Briggs (JBI). Las búsquedas se realizaron en COCHRANE, EMBASE, LILACS, SCIELO, MEDLINE, SCOPUS y ScienceDirect. De los 2556 estudios identificados, se incluyeron 12. La IAN fue evaluada mediante indicadores antropométricos, consumo alimentario y datos clínico-biológicos. Se identificó una brecha significativa en la literatura sobre los factores sociodemográficos y estructurales relacionados con la pobreza que afectan el acceso y la disponibilidad de alimentos en poblaciones minoritarias con ECF, lo que resalta la necesidad de estudios más específicos para esta población vulnerable.

Descriptores Inseguridad alimentaria; Anemia de células falciformes; Adulto

REVIEW

Introduction

Sickle Cell Disease (SCD) is a hereditary condition originating from West African populations, caused by a mutation in hemoglobin, the protein responsible for transporting oxygen throughout the body, which is present in red blood cells. For many years, SCD was considered untreatable; however, with bone marrow transplantation (BMT), it is now curable, although this therapeutic approach is indicated only for severe cases[1].

In Brazil, mortality from SCD remains high, particularly among young adults. A time-series study conducted between 2015 and 2019[2] showed that around 7,000 deaths had sickle cell anemia as the underlying cause. Among these deaths, the majority (44%) were women of mixed or Black race, predominantly in the Southeast and Northeast regions, and over 34 years of age, highlighting greater vulnerability in this gender and reduced survival in the third decade of life.

Mortality in this population can result from various factors, particularly the intense and frequent painful crises during acute exacerbations of the disease. These crises occur due to vascular occlusion, leading to severe pain and damage to vital organs, which are responsible for numerous hospitalizations and deaths[3,4].

These factors reduce the quality of life in adults with SCD, and when exacerbated by poor adherence to treatment, malnutrition, and social aspects such as unemployment, low socioeconomic status, and low educational level, they further increase vulnerability to other complications of the disease. This scenario limits access to the only curative therapy—Bone Marrow Transplantation (BMT)[2–4]—and consequently increases mortality risk.

Painful crises, recurrent infections, and loss of appetite increase nutritional demands, and in individuals experiencing Food and Nutrition Insecurity (FNI), these demands are even greater and may worsen health status. Adequate nutrition is essential to reduce immunosuppression caused by the lack of essential micronutrients and to decrease the risk of SCD-related complications[5-7].

Several social and health factors are associated with Food and Nutrition Security (FNS). In Brazil, the definition of FNS refers to access and availability of adequate food in both quality and quantity, also encompassing economic, social, and environmental sustainability[8]. In contrast, FNI, as measured by the Brazilian Food Insecurity Scale (EBIA) – short version (2014), can be classified into three levels (mild, moderate, severe), which express the severity of food insufficiency and food security[8,9].

FNI encompasses the physical dimension, such as obesity and malnutrition, and the psychological dimension, such as concerns about food deprivation. These conditions compromise health, putting it at risk[8–11]. The most severe manifestations culminate in hunger, which can be measured through both direct and indirect FNS indicators[12].

Although primary studies on SCD aim to estimate the prevalence of FNI and characterize socioeconomic and demographic factors related to mortality and complications[13–16], most of these investigations in Brazil and worldwide have focused on pediatric populations, leaving a significant gap in understanding the impacts of FNI among adults with this condition[17,18]. Adults with SCD also face additional challenges related to socioeconomic factors, such as unemployment, limited access to healthcare services, and limited access to healthy and adequate food. These factors can worsen disease complications and, consequently, deteriorate living and health conditions.

Therefore, this study aims to map the causes and manifestations of food and nutrition insecurity in adults with sickle cell disease.

Method

This is a scoping review that followed the recommendations proposed by the Joanna Briggs Institute (JBI) methodology[19,20] and used the Preferred Reporting Items for Scoping Reviews (PRISMA-ScR) extension as a reporting guideline[19]. The protocol has already been published[21] and registered on the Open Science Framework – OSF platform (https://osf.io/hufty/).

A preliminary search was carried out in the Medical Literature Analysis and Retrieval System Online (MEDLINE via PubMed) and Embase via Elsevier (Table 1) to refine the research question, identify inclusion and exclusion criteria, verify whether there was sufficient literature to conduct a scoping review on the intended topic, assess study feasibility, and map existing knowledge.

The complete search was conducted in the following electronic databases: COCHRANE LIBRARY, Cumulative Index to Nursing and Allied Health Literature (CINAHL, EBSCO), Scopus, Latin American and Caribbean Literature in Health Sciences (LILACS) via BVS, and Scientific Electronic Library Online (SCIELO). Grey literature was not included, as it was understood that theses, dissertations, and undergraduate monographs with methodological rigor are widely disseminated through scientific evidence.

Quadro 1 - Estratégia de pesquisa preliminar e números de estudos recuperados. Feira de Santana, Bahia, Brasil, 2025.

Base de dados	Estratégia de pesquisa*	Quantidade de estudos recuperados
PUBMED (MEDLINE)	*(food insecurity) OR (food Rationing) OR (diet quality) OR (housing instability) OR (healthy food) OR (consumption food)) OR (inequalities social) AND (sickle cell anemia) OR (sickle cell disorder) OR (sickle cell disease) AND (adult)*	1052
EMBASE (ELSEVIER)	*(adult):ab,ti OR ('groups by sex') OR ((female):ab,ti) OR (('older adults'):ab,ti) OR (('middle aged'):ab,ti) OR (('young adult'):ab,ti) OR ((girl):ab,ti) AND (('sickle cell anemia'):ab,ti) OR (('sickle cell'):ab,ti) OR ((anemia):ab,ti) AND (('food safety'):ab,ti) OR (('standard of living'):ab,ti) OR (('food intake'):ab,ti) AND [2000-2023]/py*	12.346

Source: Author's own elaboration/ MeSH and EMTREE descriptors, and their respective correlates.

Studies were included without language restrictions, and the search period started from the year 2000; this time frame is justified because, in that year, Heads of State agreed at the United Nations Millennium Summit on strategies aimed at reducing world hunger. The research question, study objective, and descriptors were defined using the mnemonic combination Population, Concept, and Context (PCC): P – Population: Adults with Sickle Cell Disease; C – Concept: Food and Nutrition Insecurity; C – Context: not specifically defined. Opinion papers, integrative reviews, and theoretical essays were not included. Based on the PCC mnemonic, the following research question was formulated: How have the causes and manifestations of food and nutrition insecurity been mapped among adults diagnosed with sickle cell disease?

Studies including individuals with sickle cell disease and food and nutrition insecurity between 19 and 44 years of age and middle-aged adults between 44 and 64 years of age (DeCS) were considered. This categorization follows the **Health Sciences Descriptors/Medical Subject Headings (DeCS/MeSH)**[22].

For the concept of Food and Nutrition Insecurity (FNI), the adopted definition was the lack of access, availability, regularity, and utilization of food, regardless of whether mild, moderate, or severe, in individuals with sickle cell disease. In Brazil, authors in this field have characterized FNI as mild, moderate, or severe[23], while globally, FNI is assessed using both direct and indirect indicators.

The studies included in this review addressed FNI among individuals with sickle cell disease, considering aspects of the nutritional dimension and food dimension, inherent to its concept[8]. As an exclusion criterion, studies involving individuals with sickle cell trait or thalassemia were not considered.

After the search, all studies were compiled and imported into the EndNote Web 20 reference manager (Clarivate Analytics, PA, USA) to organize the material and remove duplicates. The records were then managed in Rayyan[24] for unified processing, including study identification, screening, and selection. Individual information was extracted on the study method, manifestations of food and nutrition insecurity, and conceptual definitions.

Two independent reviewers analyzed the titles and abstracts individually, based on the inclusion and exclusion criteria. In case of disagreement, a third reviewer made the decision, and, if necessary, consensus was reached through discussion. Full-text reading was performed independently and blinded. Reasons for article exclusion are presented in the PRISMA Flowchart (Figure 1).

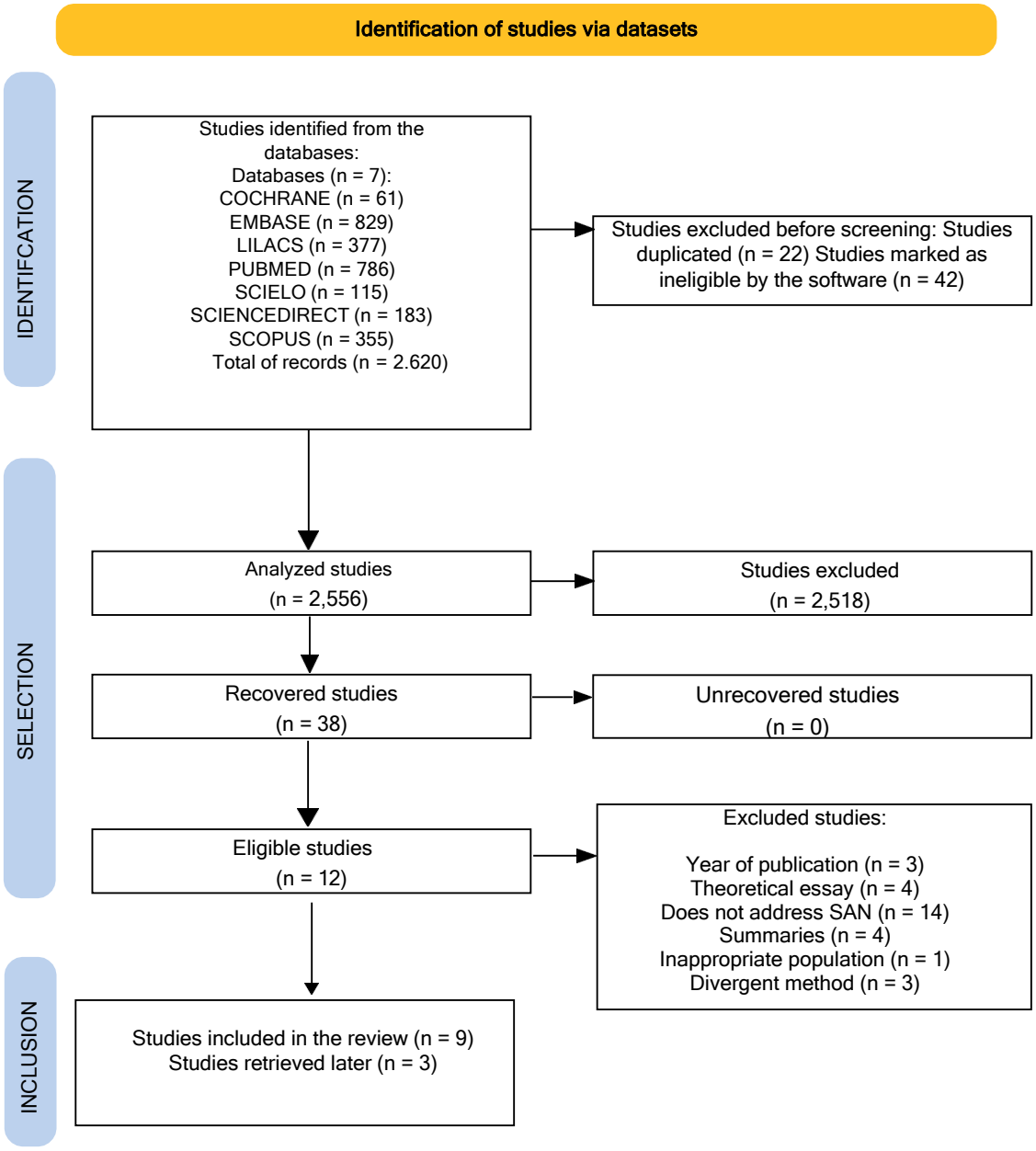

Figure 1. PRISMA Flowchart.

At the time of data extraction, the data extraction tool (Table 2), developed by the reviewers based on the methodological guidance for scoping reviews from JBI[19,20], was used. The authors of the articles were also contacted to provide the full text and clarify the research methodology.

Chart 2 – Databases in correspondence with the search strategies. Feira de Santana, Bahia, Brazil, 2025..

Database (n of retrieved articles)	Search strategy
COCHRANE LIBRARY (N=61)	"nutrition" in Title Abstract Keyword AND "insecurity" in Title Abstract Keyword AND "sickle cell anaemia" in Title Abstract Keyword OR "sickle cell disease" in Title Abstract Keyword OR "insecurities" in Title Abstract Keyword
EMBASE/ELSEVIER (N=829)	(adult):ab,ti OR ('groups by sex') OR ((female):ab,ti) OR (('older adults'):ab,ti) OR (('middle aged'):ab,ti) OR (('young adult'):ab,ti) OR ((girl):ab,ti) AND (('sickle cell anemia'):ab,ti) OR (('sickle cell'):ab,ti) OR ((anemia):ab,ti) AND (('food safety'):ab,ti) OR (('standard of living'):ab,ti) OR (('food intake'):ab,ti) AND [2000-2023]/py
LILACS (N=377)	insecurity OR sickle cell OR sickle cell anaemia OR nutritional
PUBMED/MEDLINE (N=786)	(food insecurity) OR (food rationing) OR (diet quality) OR (housing instability) OR (healthy food) OR (food consumption) OR (social inequalities) AND (sickle cell anemia) OR (sickle cell disorder) OR (sickle cell disease)
SCIELO (N=115)	ab:(food insecurity) OR (ti:(food insecurity) AND (ab:(sickle cell disease)) OR (ti:(sickle cell disease)) OR (ab:(sickle cell anemia) OR (sickle cell anemia) OR ti:(food insecurity))
SCIENCEDIRECT (N=183)	insecurity OR sickle cell OR sickle cell anaemia OR nutritional
SCOPUS (N=355)	Food AND Insecurity AND anaemia

The articles included in this study are presented, grouped, synthesized, and their results organized in tables and charts, guided by the PRISMA-ScR flow diagram[25],[26].

Results

Across the seven electronic databases (Cochrane = 61; EMBASE = 829; LILACS = 377; Medline/PubMed = 786; Scielo = 115; ScienceDirect = 183; Scopus = 355), a total of 2,556 studies were initially identified as potentially eligible. Of these, 2,518 were excluded for not meeting the inclusion criteria. A total of 38 studies were deemed eligible for full-text review by both reviewers. For the final analysis, nine studies were included, plus three additional ones retrieved after screening the reference lists (Figure 1).

Studies not available through the CAPES Journals Portal were requested from collaborators via the ResearchGate platform, where access to two studies was obtained. Additionally, clarifications were obtained by email regarding two works that were only published as part of final reports in Medical Residency Congresses, and one more article was also accessed in this way.

Most studies were conducted in North (6) and South America (3), followed by Africa (3), with a significant occurrence in the United States, followed by

Brazil, Tanzania, Nigeria, and Sudan. The majority adopted a quantitative design (11) and one was qualitative (1): most were observational (11) and one case report; seven had a cross-sectional design, three were longitudinal, and one did not specify the study design in its methodology.

Regarding the year of publication, most were published after 2018, while three were from earlier years (2004, 2005, and 2011). English was the predominant language (11 articles), with only one published in Portuguese. Most journals were international, with themes in Internal Medicine (4), Hematology (5), Nutrition (2), and only one national journal in the multiprofessional area (1). The main characteristics of the studies are presented in Table 3.

As for the setting of the studies, most were conducted in clinical-hospital environments, including hospitals (7), medical clinics (4), and one blood center (1). Regarding demographic data, all included both sexes and adults, with three studies also including children and adolescents. In terms of clinical characteristics, most participants had homozygous sickle cell anemia (HbSS) (Table 3).

Table 3. Distribution of studies retrieved from the sources of evidence, according to the dimensions of FNI, FNI assessment, causes of FNI, and manifestations of FNI. Feira de Santana, Bahia, Brazil, 2025.

	RESULTADOS EXTRAÍDOS DAS FONTES DE EVIDÊNCIAS				
No.	**Study Title**	**SCD Dimension**	**SCD Assessment**	**Cause**	**Manifestations**
1	Food Consumption of People with Sickle Cell Anemia in a Middle-Income Country	Food access	Dietary intake; Clinical-biological indicators	Socioeconomic factors	Inadequate micronutrient intake; high consumption of inappropriate foods
2	Community-level socioeconomic distress is associated with nutritional status in adults with sickle cell anemia	Food access, availability, and nutrient utilization	Anthropometric and clinical-biological indicators	Community- and individual-level access barriers	Inadequate BMI; micronutrient deficiencies
3	Characterising the prevalence of overweight and obese status among adults with sickle cell disease	Nutrient utilization	Anthropometric indicators	Not explored	Inadequate anthropometric status
4	An Intensive Intervention to Reduce Readmissions for Frequently Hospitalized Patients: CHAMP	Food access and availability; social determinants; social support	–	Social and psychosocial vulnerability	Limited access to food

	RESULTADOS EXTRAÍDOS DAS FONTES DE EVIDÊNCIAS				
No.	**Study Title**	**SCD Dimension**	**SCD Assessment**	**Cause**	**Manifestations**
	Randomized Controlled Trial				
5	Micronutrient levels and haemato-biochemical status of patients with sickle cell anaemia	Nutrient utilization	Clinical-biological and anthropometric indicators	Not explored	Inadequate BMI; micronutrient deficiencies
6	Nutritional and hematological status of Sudanese women of childbearing age with steady-state sickle cell anemia	Nutrient utilization	Anthropometric indicators	Food access; socioeconomic factors	Inadequate anthropometric status; inadequate BMI
7	Dialogues on Food and Eating in Patients with Sickle Cell Anemia	Food access	Dietary intake	Socioeconomic factors	Inadequate dietary intake
8	Lipid Profile, Nutritional Status and Severity Biomarkers in Adults With Sickle Cell Anemia	Nutrient utilization	Dietary intake; clinical-biological indicators	Dietary intake	Inadequate anthropometric status; inadequate dietary intake
9	Serum 25-Hydroxyvitamin D and Diet Mediates Vaso-Occlusive Related Hospitalizations in Sickle-Cell Disease Patients	Nutrient utilization and food access	Dietary intake; supplementation; clinical-biological indicators	Hospitalization; food access	Micronutrient deficiencies
10	Nutritional status, hospitalization and mortality among patients with sickle cell anemia in Tanzania	Nutrient utilization	Anthropometric indicators	Hospitalization	Inadequate anthropometric status
11	Nutritional deficiencies in iron overloaded patients with hemoglobinopathies	Nutrient utilization	Clinical-biological indicators	Blood transfusion; dietary intake	Micronutrient deficiencies
12	Moderate Chronic Pain, Weight, and Diet Intake in Adult African American Patients With Sickle Cell Anemia	Nutrient utilization and stability	Anthropometric indicators	Functional capacity; hospitalization; dietary intake	Inadequate anthropometric status

Regarding the instruments adopted, different tools were used to assess food and nutrition insecurity (FNI), including direct and indirect methods, such as dietary intake, 24-hour dietary recall (2), food frequency questionnaire (1), clinical and biological examinations (7), anthropometric assessment (6) and Body Mass Index (BMI) (6), as well as socioeconomic determination forms (4).

In relation to the characteristics, signs, symptoms, and complications inherent to sickle cell disease, the following were employed: electrophoresis for diagnostic confirmation (4), history of dactylitis (1), number of hospitalizations (5), frequency and intensity of pain (2), blood transfusion (2), and use of chelators (2), analyzing their influence on nutritional status (Table 4).

Table 4. Instruments and clinical-laboratory characteristics used for assessing food and nutrition insecurity and clinical complications in adults with sickle cell disease.

Table 4. Characteristics of the studies retrieved from the sources of evidence. Feira de Santana, Bahia, Brazil, 2025.

No.	Study Title	Author(s)	Study Design / Population	Study Location	Method and Assessment Instruments	Period
1	Food Consumption of People with Sickle Cell Anemia in a Middle-Income Country	Teixeira TV et al.	Cross-sectional / 215 adults aged 19–59	Brazil	Dietary intake; BMI; Socioeconomic Classification Criteria (CCEB)	2023
2	Community-level socioeconomic distress is associated with nutritional status in adults with sickle cell anemia	Syeda Akila et al.	Cross-sectional / 332 adults aged 24–42	USA	Anthropometric assessment; Biochemical profile; Vaso-occlusive pain assessment; Georeferencing	2023
3	Micronutrient levels and haemato-biochemical status of patients with sickle cell anaemia at a tertiary hospital in Abakaliki, south-eastern Nigeria: a cross-sectional study	Nnachi OC et al.	Cross-sectional / 120 adults	Nigeria	Electrophoresis; Anthropometric assessment; BMI; Biochemical and micronutrient profile	2022
4	Characterising the prevalence of overweight and obese status among adults with sickle cell disease	Stephanie O Ibemere et al.	Cohort (2016–2021) / adults aged 20–45	USA	Medical records; Psychoemotional questionnaire; Blood transfusion history; Anthropometric profile; BMI	2022
5	An Intensive Intervention to Reduce Readmissions for Frequently Hospitalized Patients: the CHAMP Randomized Controlled Trial	Henschen BL et al.	Action research: Randomized clinical trial / 151 adults, mean age 52	USA	Medical records; Food access (method not specified)	2022
6	Nutritional and hematological status of Sudanese women of	Ali EH et al.	Cross-sectional / 75 women aged 16–40	Sudan	Anthropometric profile; BMI; Dietary intake; Medical	2021

No.	Study Title	Author(s)	Study Design / Population	Study Location	Method and Assessment Instruments	Period
	childbearing age with steady-state sickle cell anemia				records; Sociodemographic questionnaire	
7	Dialogues on Food and Eating in Patients with Sickle Cell Anemia	Carvalho MGF et al.	Action research / 14 adults	Brazil	Interview guide	2020
8	Lipid Profile, Nutritional Status and Severity Biomarkers in Adults With Sickle Cell Anemia	Gomes ICP et al.	Controlled cross-sectional / 55 adults aged ≥19	Brazil	24h dietary recall; Anthropometric profile; BMI; Biochemical profile	2019–2020
9	Serum 25-Hydroxyvitamin D and Diet Mediates Vaso-Occlusive Related Hospitalizations in Sickle-Cell Disease Patients	McCaskill ML et al.	Longitudinal (2010–2014 and 2009–2010) / 100 adults aged 18–80	USA	Biochemical profile; Medical records; Food frequency	2018
10	Nutritional status, hospitalization and mortality among patients with sickle cell anemia in Tanzania	Cox SE et al.	Cohort (2004–2009) / 1758 participants aged 6 months–64 years	Tanzania	Medical records; Biochemical profile; Anthropometric profile; BMI	2011
11	Nutritional deficiencies in iron overloaded patients with hemoglobinopathies	Claster S et al.	Exploratory study / 67 participants aged 1.5–32	USA	Micronutrient biochemical profile	2009
12	Moderate Chronic Pain, Weight, and Diet Intake					

Source: Author; Note: SCD = Sickle Cell Disease; IAN = Food and Nutritional Insecurity).

Em relação às manifestações da IAN entre as pessoas com doença falciforme verificou-se que os estudos selecionados abordavam sobre ingestão elevada de ferro (1), estado antropométrico inadequado (04), baixo peso (2) e obesidade (2); déficit de nutrientes (3), dificuldade de acesso aos alimentos (2) e risco do consumo de alimentos ultraprocessados, vulnerabilidade social (1).

Para uma apresentação mais compreensiva da temática, optou-se em discutir os artigos por temáticas conceituais: dimensões da insegurança alimentar, avaliação da insegurança alimentar nutricional, manifestações da insegurança alimentar e sua relação com sinais e sintomas da doença falciforme.

Discussion

This study enabled an analysis of global scientific evidence regarding the manifestations and causes of food and nutrition insecurity (FNI) among adults with sickle cell disease, examining a variety of quantitative and qualitative studies that explored different dimensions of this association.

The selected studies used anthropometric indicators and biochemical tests to assess nutritional dystrophies and hidden hunger, as well as

sociodemographic data related to poverty and housing conditions. However, none of these indicators alone can determine the presence of food insecurity. Its multifactorial nature must be recognized[15], as it is not limited to the physical nutritional status but is influenced by broader social, economic, and structural factors, including structural racism. Structural racism does not depend on individual actions or intentions but is rooted in institutions and daily practices that reproduce racial inequalities in Brazil[37]. Despite its significant influence on food access and availability patterns among minority populations, including Black people affected by sickle cell disease, no studies addressing this perspective were identified.

The intersection of gender, race/color, and social class in determining food insecurity has been evidenced in households headed by Black women, who show higher prevalence of moderate and severe food insecurity compared with other groups[38],[39]. This population has historically faced multiple forms of discrimination and inequality, contributing to greater vulnerability to food insecurity. This reality is further aggravated by low educational attainment and lower per capita income, highlighting the importance of context-sensitive social and cultural approaches to addressing food insecurity among people with sickle cell disease—a racialized illness[40].

Food insecurity encompasses both psychological dimensions, such as the concern about not having regular access to food, and physical manifestations, including malnutrition and obesity resulting from so-called hidden hunger[41]. Multiple factors reduce the quality of life among adults with sickle cell disease, and when compounded by poor treatment adherence, malnutrition, and social challenges, these can worsen disease symptoms and increase the risk of complications[5],[36].

To secure access to food, individuals require income, whether through formal employment, self-employment, social transfers, or food production for those with access to land and productive resources[42]. Among people with sickle cell disease, loss of income due to inability to work during hospitalizations is frequent. In addition, they face extra healthcare costs, such as expenses for medications, medical appointments, and transportation[43], which further reduce household budgets available for food, heightening vulnerability to food insecurity.

Although some studies[27],[28],[30],[32] have explored the magnitude of socioeconomic and demographic indicators associated with food insecurity in adults with sickle cell disease, this review highlights a gap in the direct assessment of food insecurity in this group, especially concerning social determinants of health. The studies analyzed focused on dimensions such as high iron intake, inadequate anthropometric status, low weight, obesity, nutrient deficiencies, difficulty accessing food, and risk of consuming ultra-processed foods. However, addressing these dimensions in isolation does not capture the full variations and complexity of food insecurity, which involves specific challenges related to socioeconomic, cultural, geographic, clinical, and psychological factors[42].

In addition, the inability to prepare meals at home due to clinical manifestations such as fatigue or pain can lead individuals with sickle cell disease to rely on processed and ultra-processed foods. These often fail to meet

nutritional needs, increasing risks of obesity, diabetes, and food insecurity[42], especially when nutrient requirements are higher due to complications.

Over the years, studies[43–46] have shown a nutritional transition, where dietary patterns are increasingly characterized by consumption of cheap but low-quality industrialized foods rich in sugar, salt, trans fats, and additives. These findings underscore the need to consider not only food availability but also the practical challenges faced by people with sickle cell disease in maintaining a healthy diet.

Some patients require specific diets, including increased intake of folate-rich foods and restriction of iron-rich foods[2,47]. The results of this review emphasize the importance of addressing common nutritional deficiencies, such as folic acid deficiency, frequently associated with accelerated erythropoiesis in this condition.

The study by Dixit et al.[48] demonstrated that folate supplementation significantly increases serum folate levels, preventing deficiency. However, results showed no positive impact on key clinical indicators, such as hemoglobin concentration and frequency of pain crises, indicating that supplementation alone is insufficient to modify clinical outcomes. Moreover, this systematic review warned of potential adverse effects, including the risk of secondary hemochromatosis in patients receiving regular transfusions, underscoring the need for clinical monitoring and individualized nutritional care. The authors also highlighted the low quality of available evidence, largely due to older studies with weak methodological rigor, reinforcing the need for new investigations[48].

The lack of studies on FNI in adults with sickle cell disease is evident, particularly when compared to research focusing on nutritional deficits in children and adolescents. Nartey et al.[15], in their review of nutrient deficiencies in African children and adolescents with sickle cell disease, also emphasized the importance of considering not only clinical needs but also local socioeconomic and cultural determinants, highlighting the complexity of this issue across contexts. Supplementation and food fortification, though relevant strategies, require more longitudinal studies to assess their benefits and possible adverse effects.

As a mapping method, this review identified a variety of approaches used to assess food and nutrition insecurity in studies involving people with sickle cell disease. These included direct methods such as dietary intake, 24-hour dietary recall, food frequency, clinical and biological exams, and anthropometric assessment, as well as indirect methods such as BMI and socioeconomic determination forms. Each method has advantages and limitations, reinforcing the need for a hybrid approach to understand FNI in this population.

The reviewed studies also provided evidence on the association between food insecurity and sickle cell disease symptoms, showing links with disease severity, frequency of pain crises, need for blood transfusions, and use of chelators. FNI was further associated with nutritional deficiencies and impaired anthropometric status, highlighting the importance of nutritional and socioeconomic interventions to improve health outcomes.

Nevertheless, there remains a significant gap in the literature regarding direct measurement of hunger perception and its relationship with nutritional status among people with sickle cell disease, both at household and individual levels. No published studies were identified that assessed food access and

availability using a direct hunger indicator. Primary studies mainly sought to estimate FNI prevalence, characterize socioeconomic and demographic factors, and assess complications and mortality[14,16,49].

Most studies remain scarce and child-focused[50,17,18]. In the context of FNI, only one study was found that investigated the association between food and nutrition insecurity and social support[17]. In terms of reviews, only one scoping review has been published worldwide on FNI in people with sickle cell disease, and the most recent was a systematic review in Africa, describing socioeconomic and nutritional characteristics of children and adolescents with the disease[15].

Currently, several validated scales exist to assess food insecurity in different contexts, such as the Brazilian Food Insecurity Scale (EBIA)[52], the FAO Food Insecurity Scale[53], the Latin American and Caribbean Food Security Scale (ELCSA)[54], and the Food Security Scale for Bangladesh (FANTA)[55], among others. More recently in Brazil, the VIGI-INSAN methodology was proposed to evaluate food and nutrition insecurity among adults and the elderly[42]. However, none of the studies included in this review used these scales to measure the food dimension of food security in adults with sickle cell disease.

Limitations

This scoping review presents some limitations recognized by the authors. The time frame starting in 2000 may exclude earlier studies relevant to understanding the relationship between FNI and sickle cell disease.

Strengths of the present scoping review

This review made a significant contribution to advancing scientific knowledge in the field of food and nutrition, particularly regarding the practical application of FNI in adults with sickle cell disease. One of its main strengths was its ability to extend the impact of research beyond academia, encouraging the publication of academic outputs, including gray literature, while reaching civil society. This approach not only increases research accessibility but also raises awareness about the magnitude of sickle cell disease in society.

It also played an important role in identifying gaps and divergences in the current literature, stimulating new research development and promoting a rethinking of intervention strategies. By expanding databases and strengthening the available evidence, it will contribute to the design of health policies and care programs better tailored to the needs of this population. In doing so, it contributes to existing knowledge and to recognizing and addressing structural disparities that perpetuate inequalities, ensuring equitable access to adequate and healthy food for this population, regardless of race, gender, or social class, and thus promoting justice in the fight against food and nutrition insecurity among vulnerable populations.

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